

# Internet discussion forums for medical advice

*Jenni Cole, Chris Watkins*

# Interaction between spread of an epidemic and of news about the epidemic

2006-2010 EPSRC grant 'Amorphous Computation' £400,000

Vincent Jansen (Biology, PI), Chris Watkins (Computer Science) (I was on this grant by accident)

Sebastian Funk (PhD student) now a lecturer at London School of Hygiene and Tropical Medicine

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Introduced theoretical models showing that the local spread of news about an epidemic can slow or suppress the spread of the epidemic (in principle).

Idea: disease spreads on one network, and information about the disease spreads on another related network.

As people get sick, local information about the disease is generated and spreads on the information network; as uninfected people get information about the presence of the disease, they change their behaviour to avoid catching it.

Some nice models. Not applicable in practice so far.

Funk, Gilad, Watkins, Jansen **Proceedings of the National Academy of Sciences** 106 (16), 2009 (345 citations 😊)

On the feasibility of using two mobile phones and WLAN signal to detect co-location of two users for epidemic prediction

Nguyen, Luo, Watkins **Progress in Location-Based Services** 2014, 63-78

(Internally funded PhD at Royal Holloway)



Centers for Disease  
Control and Prevention  
CDC 24/7: Saving Lives, Protecting People™

## Community Mitigation Guidelines to Prevent Pandemic Influenza – United States, 2017

*Recommendations and Reports / April 21, 2017 / 66(1);1–34*

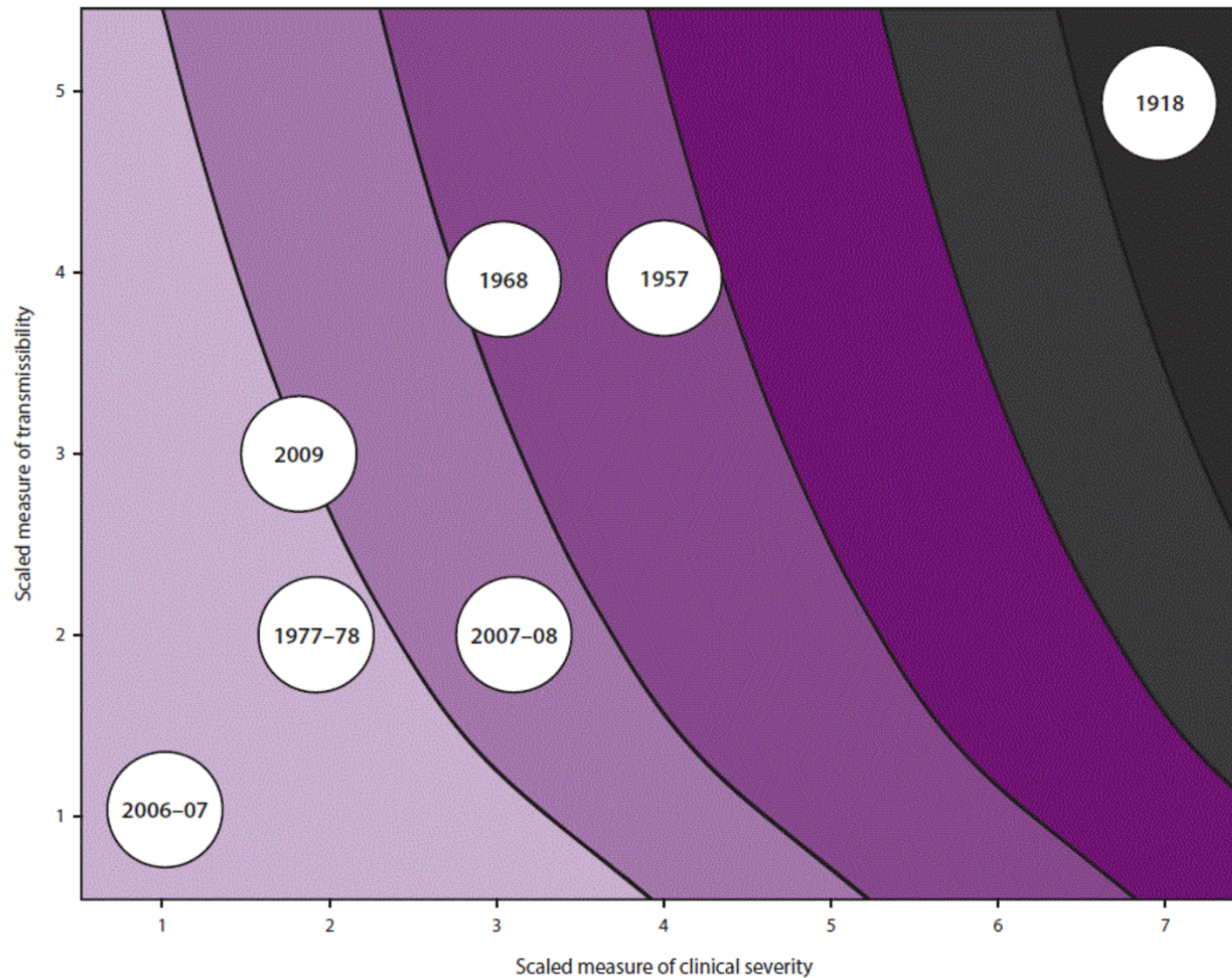
NPIs include:

- personal protective measures
  - voluntary home isolation of ill persons
  - respiratory etiquette, and hand hygiene
  - voluntary home quarantine of exposed household members
  - use of face masks when ill
  
- community measures aimed at increasing social distancing
  - school closures and dismissals
  - social distancing in workplaces
  - postponing or cancelling mass gatherings
  
- environmental measures
  - routine cleaning of frequently touched surfaces.

Several new elements [in] the 2017 guidelines ... a new section on community engagement has been included to highlight that the timely and effective use of NPIs depends on community acceptance and active participation.

Given current vaccine technology, a pandemic vaccine might not be available for up to 6 months

FIGURE 4. Pandemic Severity Assessment Framework using surveillance indicators for the refined assessment\* of an influenza pandemic on the basis of past pandemics and influenza seasons



Case fatality ratio > 1%  
Case hospitalisation > 7%

**Source:** Adapted from: Reed C, Biggerstaff M, Finelli L, et al. Novel framework for assessing epidemiologic effects of influenza epidemics and pandemics. *Emerg Infect Dis* 2013;19:85-91.

\* Colors transition from light to dark as the estimated number of deaths increases. Transmissibility: measured on a scale of 1-5 and includes school, workplace, and community attack rates, secondary household attack rates, school and/or workplace absenteeism rates, and rates of emergency department and outpatient visits for influenza-like illness. Clinical severity: measured on a scale of 1-7 and includes case-fatality ratios, case-hospitalization ratios, and deaths-hospitalizations ratios.

## Public acceptance of NPIs

- Promoting public understanding that individual action is essential ... NPI recommendations might change as new knowledge is gained.
- ...establishing communication channels that enable members of the public to ask questions and express concerns (e.g., call centers or **social media sites**)
- Ensuring that school dismissals and other NPIs are acceptable to the community during a pandemic
- Coordinating with local partners to support households complying with voluntary home quarantine (e.g., providing necessary food and supplies)
- Identifying strategies for mitigating the secondary consequences of school dismissals and other social distancing measures (e.g., modifications or cancellations of mass gatherings)
- Minimizing intervention fatigue\* during a pandemic

Many things would need to be discussed by many people during a short period of time.

# The Role of Online Discussion Forums during a Public Health Emergency

Research by **Jenni Cole**, Senior Research Fellow, Royal United Services Institute specialising in National Security, Resilience, Emergency Management



PhD studentship ~ £50,000 internally funded by Royal Holloway, 2013-2017 supervised by Chris Watkins (Computer Science), Dorothea Kleine (ICT4D), and Al Pinkerton (Geography)

- Interview study of Ebola witnesses & what information they sought and needed during the epidemic
- Accuracy and usefulness of advice in on-line discussion forums, assessed by panels of doctors.
- Observations and interviews of Reddit moderators – how they manage forum discussions, skills required
- Studied the history and growth of [reddit.com/r/ebola](https://www.reddit.com/r/ebola) during the 2014 Ebola outbreak

International employees' concerns during serious disease outbreaks and the potential impact on business continuity: Lessons identified from the 2014–15 West African Ebola outbreak. J Cole, C Watkins. **Journal of business continuity & emergency planning** 9 (2), 149-162, 2015

Health Advice from Internet Discussion Forums: How Bad Is Dangerous? J Cole, C Watkins, D Kleine. **Journal of medical Internet research** 18 (1) 2016

# Information systems during a pandemic (PHEIC)

From the Ebola witness interviews we learned:

- Different info is needed by people far-at-risk, near-at-risk, and real-at-risk
- People real-at-risk have detailed practical questions, not fully answered by official advice

Requirements for an information system:

- Standard approach to public health information is one-way communication from experts to public: this is not enough
- Need accurate collaborative question-answering on a huge scale
- From zero to millions of users in less than a month
- Should be a beacon of quality amid other social media discussion
  - Facebook and Twitter do not have quality control by moderators or collaborative voting

# reddit.com

- Fourth most visited website in the UK (alexa.com), after Google, Youtube, and Facebook
- a collection of moderated discussion forums on every subject, from disreputable to high-minded
  - some forums large: *worldnews* has 17 million subscribers, many more readers
- users can post links or self-written questions: reddit supports news aggregation, question-answering, and discussion in same forum
- moderated by volunteers: anyone can start a new forum (subreddit)
  - moderators set the policy and tone for each forum
  - can delete posts and ban undesirable users
  - many skills: moderation teams call in help from other subreddits as needed
- subtle ‘two-dimensional’ voting system for prominence and quality
  - quality of discussion is policed by moderators, and nudged by voting incentives



# Top-level posts are ordered by 'hot-score'

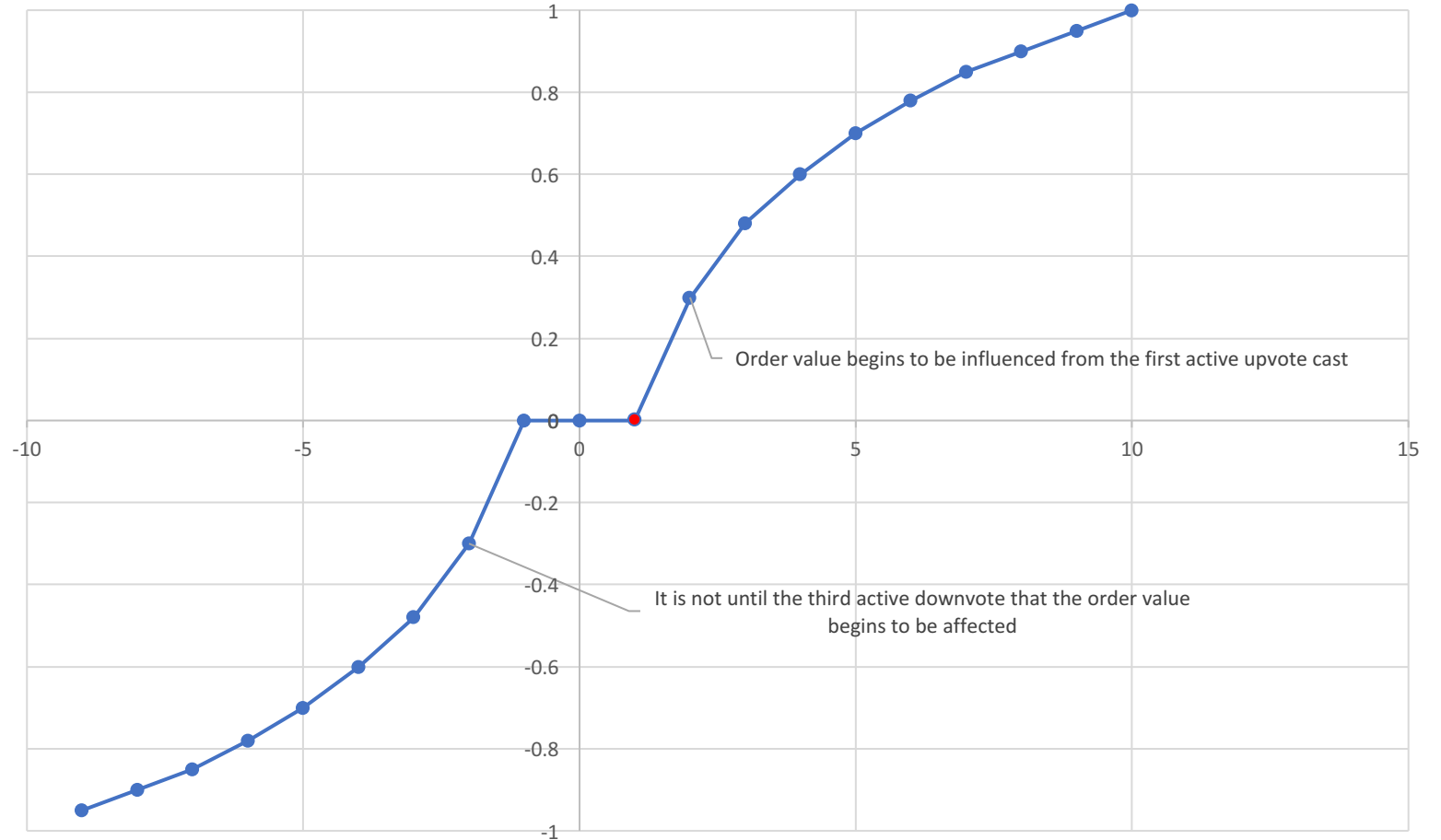
$$\text{relative\_hot\_score} = \frac{\text{sgn}(\text{upvotes} - \text{downvotes}) * \log(\text{abs}(1 + \text{upvotes} - \text{downvotes}))}{1}$$

$$\text{hot\_score} = \text{time} + \text{relative\_hot\_score}$$

One unit of time – a 'reddit day' – is 45000 seconds.

At least 3 downvotes are needed before relative\_hot\_score changes  
Originally a bug, now valued as a feature

### Relative hot-score vs upvotes - downvotes



# Each **post** has an associated tree of **comments**

At each node of the comment tree, the child-nodes are ordered by the 'best' scoring

$\text{best\_score} = \text{lower\_confidence\_bound\_of\_Bernoulli\_parameter}(\text{\#upvotes}, \text{\#downvotes})$

Originally suggested by Randall Munroe (author of XKCD)

No additional theory (?)

Comments down-voted below threshold are displayed in collapsed form: not even trolls like this.

No restructuring of comment-tree according to votes.

Child-comments can have higher scores than their parents, but scores not propagated up tree

Aim of 'best\_score' is to allow good later comments to overtake earlier mediocre comments

Partially successful.

All vote scores now not fully visible to prevent gaming by bots: only partially successful.

# Reddit is like a rack of magazines

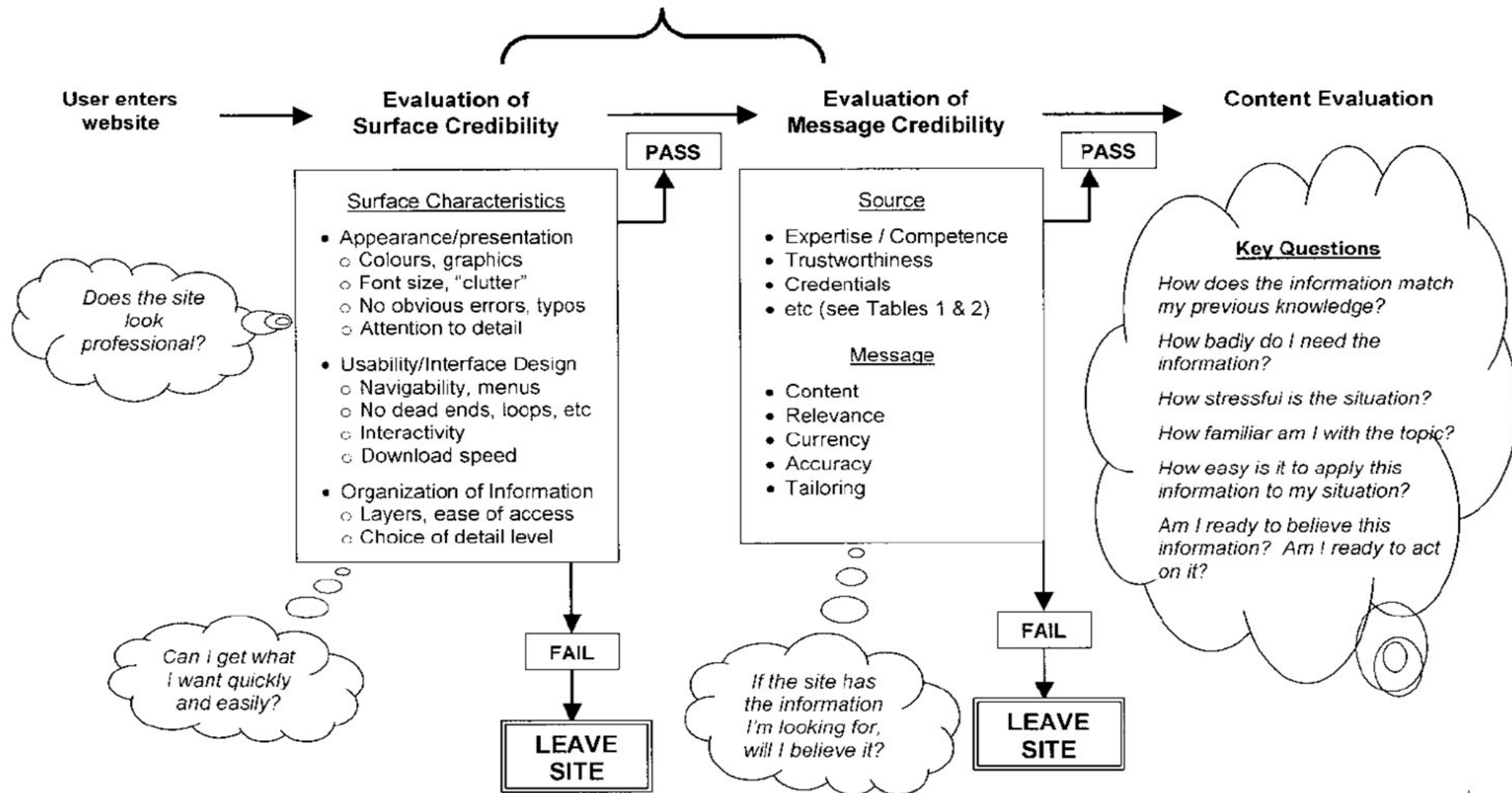
- 10,000s of subreddits, each one like a continuously published magazine
  - Range from the scurrilous and pornographic to the sober and high-minded
  - Subreddits such as /r/conspiracy and /r/The\_Donald like fake news and generate it
  - Subreddits such as /r/worldnews seek to discuss only correct and reliable news
  - Hypothesis: the nature and purpose of a subreddit is made clear to users, and users know what type of material they are reading, in the same way that they expect different news in “The Sun” and “The Guardian”
  - Users can avoid an echo chamber by subscribing to a mix of subreddits
- each subreddit is entrepreneurially created, promoted, and run by its moderators
- moderators **cannot** affect voting (integrity of voting is important)
- moderators **can** delete posts and comments, and suspend/ban users, and set the tone of discussion

Levels of quality control on reddit

	<b>INFLUENCE POOR QUAL INFO</b>	<b>INFLUENCE HIGH QUAL INFO</b>
<b>Admins</b>	Close down subreddits Force offensive subreddits to go private Remove a lead moderator	Handover an abandoned/poorly moderated sub to a new moderator
<b>Moderators</b> - access to moderation tools and system privileges	Counter claims in posts and comments Remove content Ban posters Ban domains Flair low quality Set rules Downvote	Start subreddits Designate approved posters Assign other moderators Post good quality information Comment on other posts Upvote
<b>Approved posters</b> - some system privileges	Counter claims in posts and comments Report bad information Downvote	Post good information immediately Comment favourably Upvote good information
<b>Registered users</b>	Make comments (may be delayed) Report bad information Downvote	Post good information (may be delayed) Comment favourably Upvote good information

# A model of how users evaluate sources of on-line information (Wathen and Burkell 2002)

(it is unclear from existing research whether these are simultaneous or staged)



# Traffic on r/ebola in 2014

	SUBSCRIBERS	UNIQUE VIEWS	PAGE VIEWS
Jul 2014	130	1,698	6,839
Aug 2014	1,073	26,195	167,087
Sep 2014	4,636	55,793	556,473
Oct 2014	14,192	446,497	5,017,046

**Context shifts:** changes in types of question asked as situation changes

**Community shifts:** changes in the types of people using the subreddit

Many new ignorant users => lower quality voting, many repeated questions

e.g. Repeated posts implying that Ebola could become airborne were strongly upvoted, even though each such post was immediately refuted in the comments below

Problems of scale – need to recruit extra moderators.

Problems of racism, marketing, trolling.

(Changes needed to automoderator, spam filter; specialist moderators recruited to deal with racism and trolling.)

# /r/ebola metrics (Ebola)

News, Information and Discussions about the Ebola virus.

Subscriber Growth

Total Subscribers

Rank

0 Comments

Compare ▼

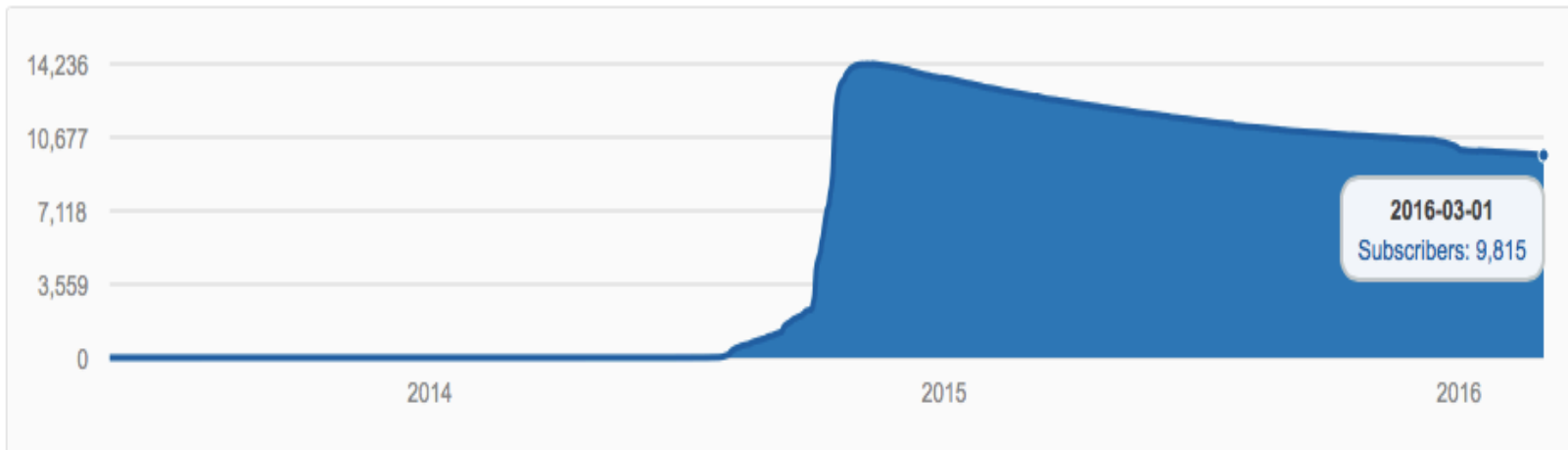
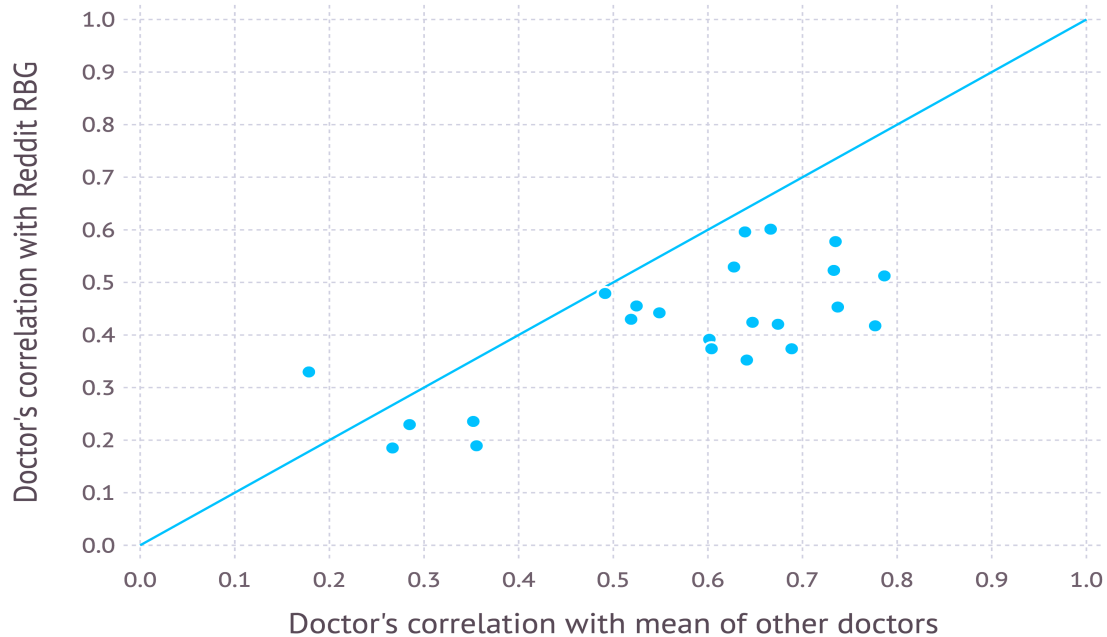


FIG 26: *Subscriber growth on r/ebola. The first upward curve corresponds with the first cases of Ebola on U.S. soil and the second, more vertical upward curve, corresponds to the first cases diagnosed on U.S. soil.*

# Quality of medical information on reddit: assessment by doctors

Comment ranking as assessed by 27 doctors:



Correlation between each doctor's score with the mean of other doctors and each doctor's correlation with the (scaled) reddit best score ordering.

Information quality, completeness, and usefulness (entire threads from chronic condition subreddits)

Small study using assessment by doctors:

- Information in chronic condition subreddits mostly accurate, complete, useful
- A minority of doctors were unwilling to rate any information from a discussion group highly

A more robust finding, in agreement with previous literature:

Extensive active searching for bad or harmful information in sober discussion groups failed to find any.



# Conclusions

- medical advice in anonymously moderated reddit forums is accurate and useful, with high respect for scientific medicine
- reddit forums can handle sudden growth in the number of users and 'context shift' in the types of questions asked
  - call in specialist volunteers from the community of reddit moderators
  - request expert advice from science subreddits
  - can effectively police discussion quality (aided by 2D voting)
- BUT: amateurs; patchy coverage; legal vacuum.

# Policy recommendations

The NHS and Public Health England should increase their support and liaison with moderated internet forums and the communities of volunteer moderators, to enable:

- moderated forums on specific diseases and medical conditions
- rapid implementation of 'beacon' subreddit(s) for collectively intelligent news aggregation and question-answering during a pandemic

# The world's most effective 'volunteer communities' ?

**Wikipedia** – 130,000 people have edited in the last 30 days  
10,000 editors with special permissions

**Reddit** – 26,000 moderators: typically spend one hour per day

**StackOverflow** – 40,000,000 visitors per month  
13,000,000 questions asked so far

**TripAdvisor** – content provided by reviewers.

In each case, a small company/foundation implements a 'gamified conversation'

Content is provided, moderated, and evaluated by a hierarchical community of tens of thousands of volunteers.

What else is possible? Could comment-boards in newspapers and blogs be